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Reducing Collusion Between Family Members and Clinicians of Patients Referred to the Palliative Care Team

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Abstract

Objective: *Collusion* refers to a secret agreement made between clinicians and family members to hide the diagnosis of a serious or life-threatening illness from the patient. Our goal was to reduce the rate of collusion among the family members of patients referred to our institution's palliative care service such that 80% of patients would be aware of their diagnosis within four weeks of referral to the service. We aimed to achieve this target within six months of starting the project.

Methods: We undertook a clinical practice improvement project using the methodology of Brent James et al of Intermountain Health to see how we could reduce collusion among clinicians and family members of patients with advanced-stage cancers. This strategy included creating awareness among patients, family, and clinicians of the problems with collusion from the standpoint of each group; adopting an empathetic and compassionate approach to communication; using pamphlets; seeking patients' views; empowering families to reveal the truth to patients; and supporting patients and families until the last moment of each patient's life.

Results: Between December 2004 and June 2008, 655 patients with advanced-stage cancers were referred to us. We were able to maintain an average awareness rate of nearly 80% of patients starting in February 2005, when we implemented awareness measures.

Conclusion: The deeply entrenched cultural practice of collusion can be changed with simple strategies based on the universal principles of medical ethics and best practices.

Introduction

Collusion, in the medical context, happens when a patient's family acts with attending clinicians to conceal a life-threatening or serious illness from the patient. This usually occurs at the family's request and is the default practice in many Asian cultures.[1] It is contributed to, in no small part, both by the widespread practice of physicians disclosing a diagnosis to a patient's family members before revealing it to the patient and by clinicians' underestimation of the information needs of patients.[2,3] Clinicians may also regard collusion as an easier option than telling the truth because it reduces their own stress and anxiety.[4]

Table 1. Reasons families choose to keep a diagnosis from a patient

Disclosure causes the patient to lose hope
Disclosure leads to depression
Disclosure hastens the progression of the illness and death
Disclosure increases the risk of patient suicide
Disclosure may cause psychologic pain for the patient
Family members themselves may not be aware of the nature and severity of the illness
Family members may be in denial
Family members may be in conflict

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Numerous Asian and European studies have shown that up to 60% of cancer patients may not be aware of their diagnoses,[5,6] although more than 90%, if given the choice, would choose to be told the truth.[2,7] A preliminary survey conducted at our hospital in Singapore in 2004 revealed the following characteristics of patients referred to our palliative care service:

- Unaware of their diagnosis at time of referral: about 70%
- Would like to know about their illness: 67%
- Would like to know whether the illness is life-threatening: 54%
- Would choose to know the prognosis in terms of their remaining life expectancy: 46%.

However, when their families were interviewed, the overwhelming majority of family members would rather not have patients be aware of the life-threatening nature of their illness (91.4%) or of the prognosis in terms of the life expectancy (95.7%).

Singapore is an island state of about four million inhabitants located at the southernmost tip of mainland Southeast Asia. It has a multiethnic population made up mainly of Chinese (75%), Malays (14%), and Indians (9%). Many of the world's major religions are represented in the nation: Christianity, Islam, Hinduism, and Buddhism.[8] Because Singapore's culture is predominantly Asian, the Asian practice of collusion, in which the patient abrogates autonomy to his or her immediate family members, is prevalent. Collusion is much less common in predominantly Western countries such as the United Kingdom and the US. Nonetheless, with globalization and transmigration, there are now large numbers of Asians living in the US where collusion is or may become a problem.[9]

The reasons families would choose collusion over revealing the truth to the patient are summarized in Table 1, and the reasons why collusion goes against best clinical practices are shown in Table 2. To address the problem of collusion in the hospital setting, we undertook a clinical practice improvement project adopting the methodology of James et al,[10] which has been further developed and systematized by Wilson and Harrison.[11] We sought to reduce the rate of collusion among patients referred to the palliative care service

Table 2. Why collusion goes against the principles of best clinical practices

Patient factors
Collusion is antithetical to patient autonomy and to the right to self-determination
Revealing the diagnosis to relatives before revealing it to patients breaches patients' right to medical confidentiality
Patients are unable to give informed consent if they are not aware of the underlying illness and thus may not obtain appropriate or optimum and timely treatment
Patients may not be able to complete unfinished business and tasks prior to their deaths
Patients who sense something amiss may come to distrust their relatives and clinicians
Many patients suspect the diagnosis anyway, given their symptoms and physical deterioration
Family factors
Family members will have to bear the burden of being untruthful or even deceptive to their loved ones, which may lead to guilt later
A barrier to communication is erected as family members become avoidant at a time when they are most needed by patients
Families will have no guidance in making treatment decisions, especially closer to the end of life
Clinician factors
Collusion results in a breakdown of the clinician–patient relationship and a loss of trust between patients and clinicians
Clinicians may face treatment noncompliance from patients and may be unable to provide optimal treatment, such as radiotherapy and chemotherapy

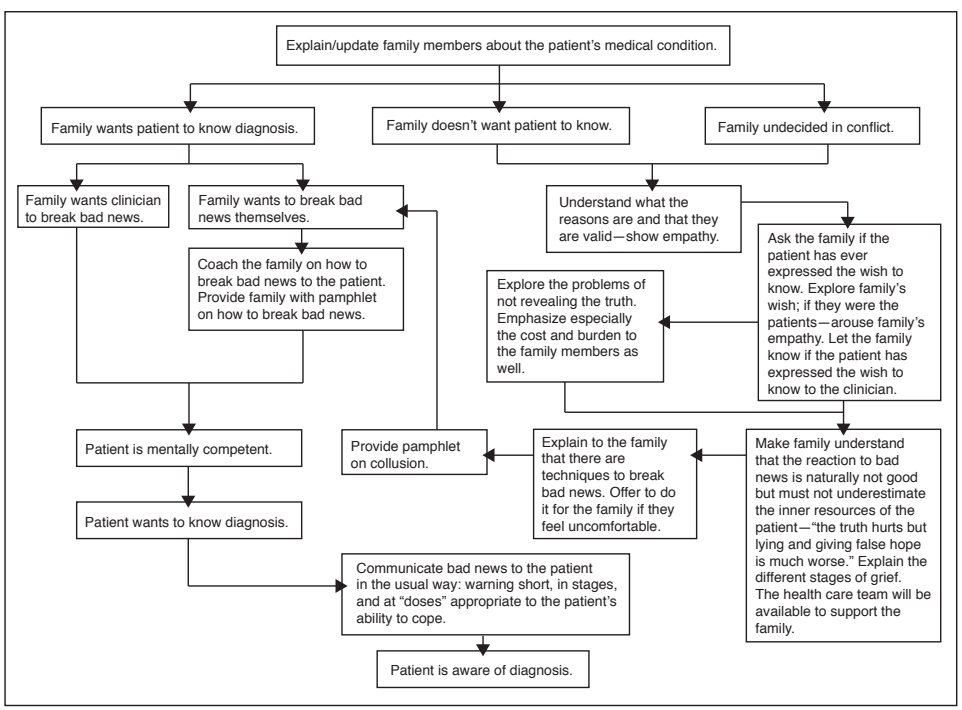

Figure 1. The root causes of collusion.

such that 80% of them would be aware of their diagnosis within four weeks of referral to the service. We aimed to achieve this target within six months of starting the project.

Methods

Defining the Problem

This project was carried out in Alexandra Hospital, a 400-bed district general hospital located in Singapore. Its main specialties are general medicine, geriatric medicine, orthopedic surgery, and general surgery. The palliative care service sees about 300 patients a year.

To begin tackling the problem of collusion within the palliative care service, we created a flow chart detailing the stream of information from the time that a diagnosis of a terminal or life-threatening illness is confirmed to the time at which a patient is fully aware of the diagnosis. We found some important factors that led to collusion (Figure 1). It was evident to us that families and attending physicians were the two most common groups of "factors" leading to the high incidence of collusion in the inpatient setting, with the former being more important than the latter. Hence, we looked in greater detail at the possible reasons families may choose collusion over telling the truth and developed a Pareto chart (Figure 2). As we studied the reasons in greater depth, we realized that the overarching theme of almost every way in which collusion was perpetuated had to do with communication or the lack of it. Hence, we devised a strategy to tackle it from a mostly communicational standpoint.

Strategies for Intervention

The first step was to create awareness that collusion was indeed a huge problem among the terminally ill and why, in most instances, it was detrimental to the care of these patients and went against the most basic ethical principles of modern medicine. We then went on to adopt a multipronged approach to tackle this problem (Table 3) and devised an algorithm (Figure 3) to manage collusion.

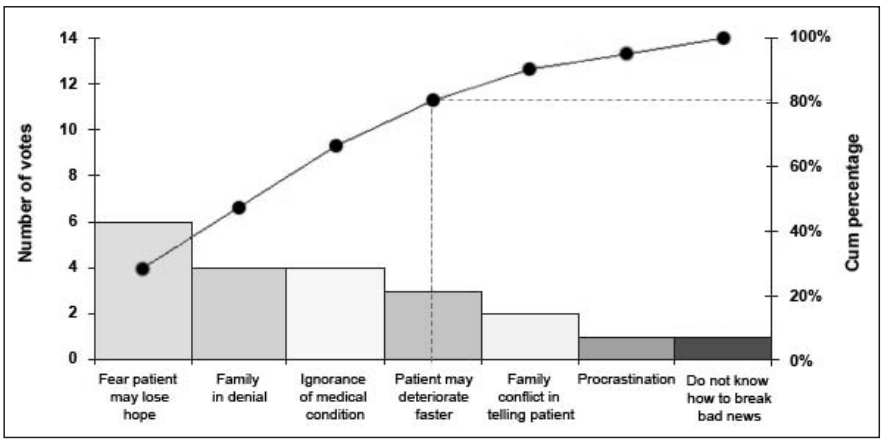

Figure 2. Families' reasons for choosing collusion.

The key points in the strategy adopted were:

- Acknowledging the problem, making the primary teams aware that collusion was generally inappropriate for patients and their families and should be addressed as soon as possible. We appointed a champion in each of the four main departments to promote awareness of collusion.
- Making family members aware of the gravity of the advanced stage

Table 3. Multipronged strategy to tackle collusion in the inpatient setting

Family-targeted strategies
Ensuring that family is fully aware of diagnosis and prognosis
Explaining the reasons and problems of collusion (reinforced with a pamphlet)
Explaining to the family how breaking bad news is conducted (reinforced with a pamphlet)
Offering to help break bad news on behalf of the family
Counseling the family on possible reactions to bad news and reassuring them that the patient will be able to cope with the families' support and care
Reassuring family members about continual care and support for the patient and for them in dealing with the terminal illness even after the diagnosis is revealed
Staff-targeted strategies
Creating awareness and addressing the issue of collusion head-on
Making it routine to address this issue for all patients with a life-threatening or terminal illness
Appointing clinician champions in the four major departments of the hospital who work to create awareness of collusion
Encouraging staff to attend workshops on breaking bad news, held regularly by the hospital's Grief and Bereavement Committee
Other strategies
Developing a protocol to deal with collusion (see Figure 3)
Conducting family conferences specially designed to resolve conflicts between family members about whether to disclose the diagnosis

of the life-threatening disease and the need to break the bad news in a timely manner. The biggest challenge was to convince the family to allow the truth to be told to the patient. The burden of collusion was explained in an empathetic and compassionate way, with an emphasis of its cost to the patient as well as to loved ones. It was important for family members to realize that although in nearly all cases, reactions to bad news is not good, they must never underestimate the coping resources of the patient, especially given the support of both informal and professional caregivers.

- Involving the patient in deciding the level of knowledge that s/he had of the illness. Our sense was that one very important deciding factor that affected the family's decision about whether to break collusion was when they were informed of the patient's wish to know the truth.
- Using two pamphlets to explain the points we were trying to make 1) about the reasons for collusion and the burden it exerts on patients and family members and 2) about techniques for breaking bad news. The former helped the family understand the issues at hand, in their own time, and acted as a memory aid for their later contemplation. The latter pamphlet empowered family members to break the bad news to the patients themselves. These pamphlets can be obtained from the authors on request.

Results

Figure 4 shows the proportion of patients who were aware of the diagnosis, from December 2004 through June 2008. The measures were implemented during a one-month period in February 2005. With the exception of December 2005, when the number of referrals was at its lowest, we were able to maintain an average awareness rate of nearly 80% as a result of our interventions. The rate was sustainable for a period of more than three years. The awareness rate was arrived at by dividing the number of patients who were aware of the diagnosis within four weeks of referral to the palliative care service by the total number of referrals for the whole month. The numerator excluded those whose families adamantly refused to have the diagnosis revealed to the patient and those who had severe cognitive impairment, which made it impossible for them to grasp the significance of their illness. During the project, 655 were referred to the palliative care service.

Discussion

Telling the truth about serious or terminal illnesses is not a common practice in many Asian cultures. Among the Chinese, who form the majority ethnic group in Singapore and among whom the Confucian tradition is prevalent, physicians tend to approach family members first with the bad news, leaving up to family members the decision of whether to disclose the diagnosis to the patient. Families who tend to be paternalistic and overprotective usually choose collusion over disclosure. This stance, albeit misguided, is born of love and concern for the patient. These families usually have pure intentions.

This project was not so much about trying to break collusion at all costs but more about giving patients a voice. It was about respecting patient autonomy and trying to align families' decisions with those of patients. We concede, however, that there can be instances when the risk of telling the truth outweighs the benefit and in certain circumstances can even hurt the patient. These rare situations are usually manifested by the family's strong insistence on keeping the truth from the patient. We respect families'

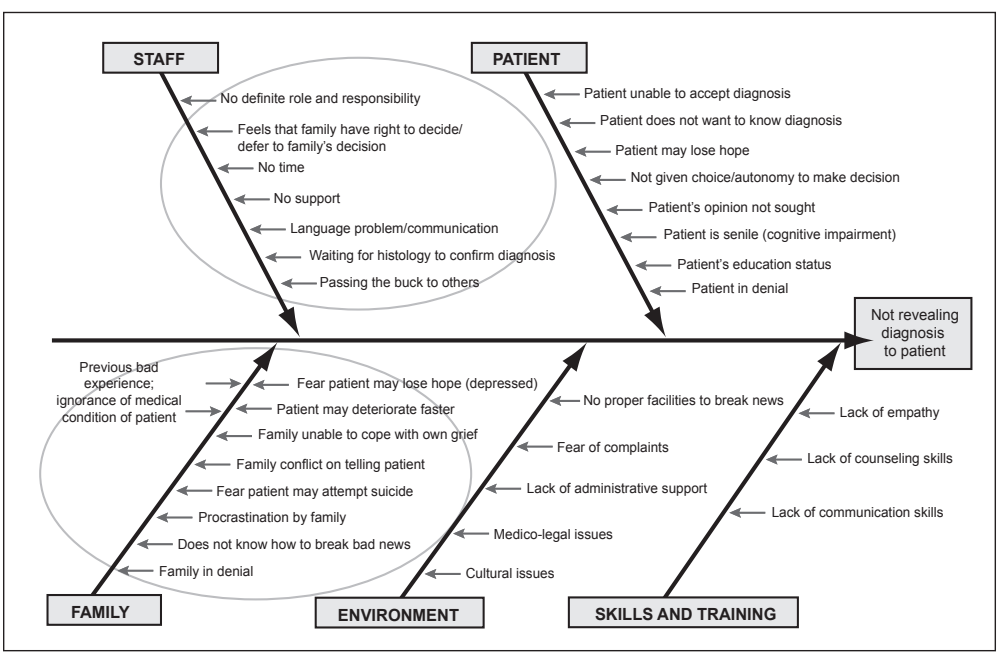

Figure 3. Algorithm for managing collusion

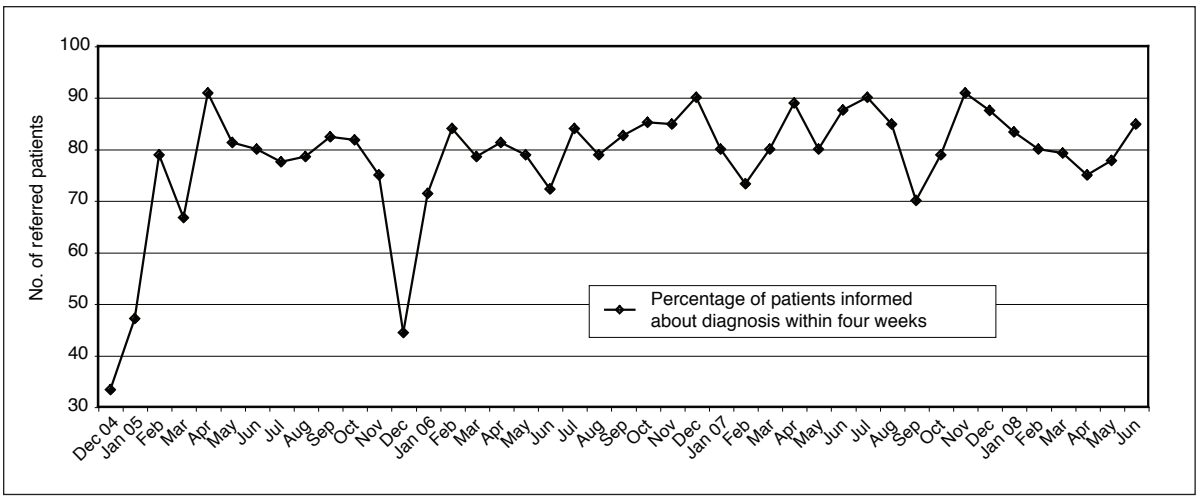

Figure 4. Patient awareness of diagnosis between December 2004 and June 2008.

wisdom too, as family members are the ones closest to the patient and hence know the patient best.

Conclusion

We have learned that collusion, despite being deeply entrenched in clinical practice in our part of the world, can be reduced with our strategies. These strategies are based on creating awareness, enabling patients to exercise their autonomy, educating family members, communicating empathetically and compassionately, and empowering family members to communicate about the difficult issues of serious illness and death. We have incorporated most of those strategies into our standard assessment of all palliative care patients. We routinely assess patients and their family members for collusion and use those strategies to manage it. Our goal was also to spread the principles espoused by this project to other departments and other hospitals within our health cluster. We achieved the latter by making numerous presentations to senior management committees and in such settings as clinical forums and team meetings. ❖

Disclosure Statement

The author(s) have no conflicts of interest to disclose.

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